

DRAFT FOR HIT POLICY COMMITTEE

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Submitter:

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Dear Dr. Mostashari and Committee Members:

I'm pleased to have the opportunity to share the insights I've gained over the past 15 years as a physician trained in surgery and a product strategist for WebMD, Press Ganey, and most recently Healthline Networks, on how to incorporate patient-generated data into the requirements for electronic health record systems. I've focused my career on patients, their access to and management of their own health information, the use of that information to drive personalized health management programs, and the gathering of the patient's voice to drive an improved care experience. In the late 1990's, as we at WebMD and others elsewhere were forging the nascent Personal Health Record industry, there were tremendous concerns over the value of patient-provided data. Even when presented with the fact that their very own patient charts were comprised in large part of patient-reported data, including their chief complaint, health history, and even findings on physical exam, physicians often expressed skepticism that patient-provided data was not as valuable as their own independent observations.

Today, however, the patient's voice is being collected and analyzed in nearly all hospitals and in a majority of large medical practices, and even driving physician compensation. Post-visit patient satisfaction using the CAHPS instruments, and the emergence of annual patient experience evaluations such as those being used for the Patient-Centered Medical Home and Accountable Care Organization initiatives, have provided a standardized way of evaluating accessibility, communication, overall ratings, and many other topics. But the methods of patient data collection used in formal and lengthy instruments are often at odds with the mobile and social nature of people and how they interact electronically with their world. I believe it's important as part of the planning for Stage 3 Meaningful Use to recognize this changing consumer electronics landscape and ensure that we're accommodating a vibrant world of patient data collection using mobile and social systems that truly engage patients.

In a recent Price Waterhouse Coopers survey, 61% of consumers responded that they are likely to trust information posted on social media by providers, and 41% were likely to share information with providers using social media. For younger individuals, these numbers are even higher. *(PWC Health Research Institute, April 2012)*

Half of Americans now own a smartphone *(Nielson)*, with Android and iOS-based smart phones leading the way. There were 35 million iPhones and almost 12 million iPads sold

last quarter, with Android-based devices doing even better. It's estimated that Hispanic and African-American households exceed smartphone use by white households by more than 20%. (*Pew Hispanic Center, 2011*) Mobile Internet devices are about to eclipse desktops in their overall Internet usage, and it's estimated that by 2015, tablets will outsell computers (*Forrester Research, 2012*).

In order to consider the standards by which EHRs should prompt and utilize self-reported data in 2016 and beyond, it is critical we recognize the electronic reality in which these certified EHR systems will live, such as....

1. Patients will use their mobile devices, with whatever security settings they desire, to interact with everyone, including their doctors. Secure portal-only interactivity will not be acceptable to most of them.
2. Compared to computer usage, mobile device usage among minority and economically underserved populations could increase health information access for these patients and reduce health literacy disparities
3. The mobile health experience cannot simply be an app on a mobile device. The mobile health experience must leverage the connectivity, location awareness, and the online relationships that the consumer trusts in order to be contextual.

EHR systems have a distinct advantage in this new reality. They have a lot of personal information gathered during patient visits. But in a changing payment environment where providers bear more of the risk for their patients' overall health and care, the role of patient-generated data must be to fill in the gaps between visits, not simply to bolster the data collected for the visit. The patient-provider relationship must become ongoing and supportive, which is exactly the way social and mobile are defining our electronic world.

EHRs, when combined with the ease of electronic access by the consumer to their own records, should spawn any number of mobile and social processes that support the patient's health goals. Targeted questionnaires, messaging programs, recommendations and targeted patient education... It's impossible to imagine it all, but creating an interface for EHR data that the user can reliably access to drive those processes, ideally with something that is easier to use than a CCD, could make the EHR central to this new ecosystem for patients. If not... If there are too many constraints... If it is simply too difficult to access, the EHR (and the providers who use them) will become LESS central to the patient's health experience, not more.

Thinking about patient-generated data in the context of quality measurement and improvement, there are several options commonly cited. Functional status, activities of daily living, health risk assessments, pre-visit questionnaires, medical history questionnaires, satisfaction surveys, and then there are specialty-specific assessments in orthopedics, cardiology and many others.

But survey instruments that gather large amounts of data at once, and leave the consumer with little in return, are likely to be tiresome for consumers. Simple questions, like "You came in to the office for back pain last week. How are you doing?" could be much more

welcome, more likely to be completed, and just as likely to give providers data that they can use to improve their care. When is the last time as a patient you were asked about how you did after the visit?

At the beginning of care for an illness, asking what the patient's expectations of their care are, and in what timeframe they expect to realize those expectations, would help providers to know how best to meet those expectation. Last year, researchers at Brigham and Women's Hospital reported that 89.4 percent of clinicians believed it was important to ask patients about expectations, but only 16.1 percent reported actually asking. (*British Medical Journal: Quality and Safety, November, 2011*).

Imagine hearing this in the doctor's office: "Six months ago, you said that your goal was to be able to walk around the block without assistance. Have you met your expectations? Have your expectations changed?"

"Last visit, I prescribed a medication. It's the yellow pill. Are you taking it? Does it seem to be working?"

"We established that you should check and record your blood sugar every morning. Have you been doing that?"

Consider how the results from these basic questions could be used for outcomes measurement consistently across all patients. Think about how simple it would be to implement, to aggregate, and to analyze. Think about how using this data routinely reinforces the importance of self-management, and how central these questions are to how patients think about their own health care.

Taking these examples – patient-reported expectations of care and patient-reported outcomes – it's easy to see how basic patient-generated data could be quite useful to health care providers and their patients...

- The physician who is tracking their patient-reported outcomes compared to their peers.
- The patient who is more satisfied knowing the practice is focused upon meeting and exceeding their expectations.
- The diabetic patient who knows the office will be checking on their self-management of their blood sugars.
- The pain sufferer who knows that the office will be using their pain log to calibrate their medication.

But this field is going to evolve rapidly, and requiring specific instruments seems premature. Instead, I recommend focusing on the ability for patients to download their record data to drive whatever services they choose, along with the ability for patients to take the data they generate between visits and store it within the EHR. Patient emails are already part of the record, and there is no reason that patients shouldn't be able to store files with their care providers. Such a "Dropbox" function for your patients to store their own information opens up a number of opportunities. If you want to see the actions your patients are taking,

then you can use it to augment the visit. If you want to start a health management program for those with chronic illness, you have a place for them to store their care plan and progress.

In conclusion, the electronic world of patients is changing rapidly, moving toward a highly mobile and socially-connected reality. There are many examples of patient-generated data that could be easy to collect and analyze, including patient-reported outcomes and expectation of care, that could create a more supportive and ongoing patient-provider relationship. But to specify any instruments now might be premature. Instead, enabling patients easy access to their EHR data in a structured format so they can drive personalized services with their own data, and then allowing them to store the data they generated between visits with the EHR, could help establish a foundation from which EHR systems can play a greater role in patient engagement going into the future.